Comparative Analysis of Stakeholder Experiences with an Online Approach to Prioritizing Patient-Centered Research Topics

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Introduction
Engaging stakeholders in prioritization and resource allocation exercises is a critical component of research. However, little is known about best methods of stakeholder engagement.

Many engagement methods require face-to-face interaction and are considered to be “high-touch.” Such approaches involve direct contact with stakeholders and therefore are time-consuming, logistically challenging, prone to cognitive bias, expensive to implement, and difficult to scale up.

As an alternative, “high-tech” engagement approaches conducted online are becoming more popular. Online approaches are scalable, can engage large numbers of stakeholders at lower cost, and allow participants to contribute remotely at their convenience. Nonetheless, there is little research on what different stakeholders think about high-tech engagement approaches.

Research Objectives
1. To explore patient/caregiver experiences with a high-tech online engagement approach for patient-centered research prioritization;
2. To compare patient/caregiver experiences with those of professional stakeholders;
3. To identify factors associated with favorable participant experiences.

Research Methods
8 online modified-Delphi (OMD) engagement panels on 3 conditions. Participants explored consensus on research priorities for pSCANNER - one of PCORI’s Patient-Centered Clinical Research Networks.

For weight management and heart failure, we conducted a patient-only panel, a clinician-only panel, and a mixed panel that included patients, clinicians, and researchers. For Kawasaki, we conducted a patient/caregiver-only panel and a mixed panel.

Each panel consisted of 2 rating rounds with a statistical feedback/online discussion round in between administered using the ExpertLens OMD platform. At the end of the last round, participants used a 7-point agreement scale to rate different aspects of the online engagement process and the ExpertLens platform.

Study sample includes 292 participants (84% of the 349 OMD panelists) across all 8 panels who completed the participant experience surveys at the end of the last round.

Measures
Willingness to use OMD again, main outcome measured by responses to the following statement: “I would like to use ExpertLens in the future.”

OMD system’s ease of use, measured by responses to the following statement: “The ExpertLens system was easy to use.”

Study participation experience index, measured by responses to 4 statements in Table 2 (α = 0.67).

Online discussion experience index, measured by responses to 8 statements in Table 2 (α = 0.60).

Active participant engagement, a dichotomous measure that defined participants as actively engaged if they answered at least 90% of the ratings questions in both rating rounds, explained at least 90% of their ratings in either of the rating rounds, and commented at least twice during the discussion round.

Data Analysis
Multivariate regression, controlling for gender, participant type, panel composition, perceived OMD system’s ease of use.

Results
Of 292 participants, 46% were patients, 36% were clinicians, and 19% were researchers (Table 1).

In multivariate models, patients were not significantly more actively engaged ((OR)=1.69, 95% CI: .94–3.05) but had more favorable study participation (β=.49; P<.05) and online discussion (β=.18; P<.05) experiences and were more willing to use OMD again (β=.36; P<.05), compared to professional stakeholders (Table 3).

Positive perceptions of the OMD system’s ease of use (β=.16; P<.05) and favorable study participation (β=.28; P<.05) and online discussion (β=.57; P<.05) experiences were also associated with increased willingness to use OMD in the future (Tables 4 and 5).

Active engagement was not associated with online experience indices or willingness to use OMD again (Tables 4 and 5).

Methodological Limitations
• Non-representative, purposive sample of participants.
• Results may not be generalizable to other conditions, tasks, or online platforms.
• Measures of participant experiences and engagement were not validated before.

Conclusions
• Participants were willing to use OMD in the future, felt that the OMD system was easy to use, had a positive online discussion experiences, and had a neutral opinion about their study participation.
• Half of participants were actively engaged in the OMD process.
• Although patients/caregivers were not more actively engaged than professional stakeholders, they had better experiences and were more willing to use OMD again.
• Positive perceptions of the OMD system’s ease of use, as well as favorable study participation and online discussion experiences, were associated with participants’ willingness to use OMD in the future. The effect sizes, however, were modest.
• High-tech approaches to engaging large numbers of stakeholders are a promising and efficient adjunct to in-person meetings. They can allow a large number of diverse stakeholders located in different parts of the country to engage at a time convenient to them, and patients appear to have more positive experiences with this approach than professionals.

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